

Activism and Health 2.0: Social Media and Global Change

An Honors Thesis (Honors 499)

by

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A handwritten signature in black ink that reads "Clare L. Chatot". The signature is written in a cursive, flowing style.

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Abstract

Over the past decade, the rise in popularity of social media and the groundswell phenomenon have had an impact on the way people interact with each other and get information. Today's "online" generation favors active, intimate relationships with organizations of all kinds, from non-profit social change organizations to health care providers. While many companies are facing hardship in the wake of these new consumer demands along with the recent economic downturn, those organizations that have turned to social media have seen success. I explain why social media provides the tools to attract and strengthen client relationships and foster activism in the social change community. I then look into how social media can be harnessed and used for public health research and development.

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Activism and Health 2.0: Social Media and Global Change

During a 2007 trip to Africa, Stacey Monk found herself volunteering at a school in the small town of Arusha, Tanzania. The school had around one hundred students and was run by a local woman named “Mama Lucy” Kamptoni, who financed the school with money she earned from selling chickens in her back yard. Monk was impressed with the level of education the students were receiving, which was much better than local alternatives, and Kamptoni’s dedication to the school. Income from students’ tuition covered the costs of students who couldn’t afford to pay, teachers’ salaries, and student meals every day¹.

Even after returning to her self-owned consulting firm in the United States, Monk could not get Mama Kamptoni’s school off of her mind. The women kept in touch and a few months after Monk’s return to the U.S., Kamptoni informed her that a developing firm had purchased the land that she rented for the school. Without funds to rent new land and build another classroom, Kamptoni’s dream of education for local children was over. This was when Epic Change was born.

Monk knew she had to find a way to raise money for Mama Kamptoni’s school, so she started a nonprofit organization, Epic Change, and shared it with her family and friends. Her goal was to provide local change-makers, like Mama Kamptoni, with the capital they needed to improve their communities². Epic Change received some donations, mostly from Monk’s acquaintances, and began to build a community of followers and supporters on Twitter. Then, in November of 2008, just six days before

Thanksgiving, Monk had an idea. What would happen, if for just forty-eight hours, the entire Twitter population worked together to share thanks and raise money?

In the days leading up to Thanksgiving, Monk and her team of volunteers worked together to come up with a strategy for an idea they called “TweetsGiving”. Two days before Thanksgiving, they challenged their supporters to tweet a message of what they were thankful for, along with a link to Epic Change’s donation page, and share the message with all of their followers. In a matter of hours, “TweetsGiving” was the number one trending topic on Twitter, and in just two days, Epic Change had raised over ten thousand dollars for the school in Arusha³. Thanks to this innovative fundraiser, Epic Change was able to build a new classroom for the children in Arusha and use the social media momentum to eventually raise nearly three hundred thousand dollars to invest in the school, which is now home to over six hundred students and consistently ranks top in its district⁴. In the words of Monk herself, “TweetsGiving simply wouldn’t have been possible without Twitter”¹.

This is not the only case of social media nurturing advocacy and changing lives. In January of 2009, Meaghan Edelstein, founder of the nonprofit organization Spirit Jump, came up with the idea of “Cards 4 Cancer Day”. As a cervical cancer survivor, Edelstein knew that a large part of her strength during treatment came from receiving encouragement cards from loved ones and supporters. Her goal of delivering one hundred thousand cards to cancer patients around the world was met after social media allowed her cause to go viral⁵. In May of 2009, Drew Olanoff was diagnosed with Hodgkin’s Lymphoma. To help deal with his diagnosis, Olanoff created the webpage BlameDrewsCancer.com, which encouraged Twitter users to “blame Drew’s cancer” for

anything negative in their lives. Olanoff found sponsors to donate one dollar to the cancer charity Livestrong for every person to use the phrase “Blame Drew’s Cancer” on Twitter, and celebrity Drew Carey eventually donated one million dollars to Livestrong in honor of Olanoff’s efforts⁶. And in December of 2009, the (RED) campaign teamed up with the social media sites Facebook, Twitter, LinkedIn, and YouTube to turn profiles and status updates red for World AIDS Day⁷. In a single day, over half a million Tweets and thousands of Facebook profiles went red to raise awareness for the global AIDS epidemic⁸. These are only a few of the success stories fueled by social media.

What is Social Media?

According to Merriam-Webster.com, social media is “forms of electronic communication (as Web sites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (as videos)”⁹. While researching for this article, I found hundreds of different definitions for the social media phenomenon. These definitions usually included phrases such as “platform for interaction”, “building relationships”, “consumer participation”, and “user generated content”. Put simply, social media sites allow people from all over the world to connect with friends and like-minded individuals and organizations and easily share their thoughts and opinions.

Interest in social media started in the late nineties with the emergence of websites such as Classmates.com and SixDegrees.com. The real rise in popularity of these sites occurred in the early two thousands with the start of communities such as Friendster, Facebook, Myspace, and LinkedIn. Today, there are hundreds of social media outlets,

ranging from blogs, interactive news sources, video and photo hosting services, and microblogging platforms. The most popular social media website, Facebook, boasts nearly 850 million monthly active users and over fifty percent of the North American population has a profile on the site¹⁰. The second most popular social networking site is the microblogging platform Twitter. There are more than 465 million Twitter accounts and over 175 million “tweets”, or microblog updates, are sent out every day¹⁰. These astonishing statistics do not even take into account other major social networking sites such as LinkedIn, YouTube, Instagram, and Pinterest, which each have millions, if not billions, of users as well.

In their book *Groundswell: Winning in a World Transformed by Social Technologies*, Charlene Li and Josh Bernoff explain why social media has become so popular in today’s society. They define the groundswell phenomenon as “a social trend in which people use technologies to get the things they need from each other, rather than from traditional institutions like corporations”¹¹. So, in a world where 11 Twitter accounts are created every second and 250 million photos are uploaded to Facebook every day, traditional media outlets are becoming a thing of the past¹⁰. Today’s consumer prefers the immediacy, innovation, and opportunities for interaction that social media provide. All organizations, especially social change organizations, can benefit from understanding this shift in culture.

Social Change Organizations

What I like to call “social change organizations”, or “SCOs” are those organizations that work to promote advocacy and fundraise on behalf of a certain cause. That cause can be anything from environmental sustainability to medical research. The organizations Epic Change, Spirit Jump, and Livestrong are all SCOs, along with the World Wildlife Foundation¹² and the Salvation Army¹³. Many people would assume that in order to be classified as an SCO, a business would be required to be not-for-profit. However, for-profit organizations can also advocate and support a mission. For example, the for-profit business TOMS Shoes uses a “one-for-one” business model to provide a pair of shoes to a child in need with every pair of their shoes purchased¹⁴. As long as a business or organization’s mission is to bring positive change to the world, it would be considered a social change organization.

There are many obstacles in the way of success for an SCO. It has been estimated that creating an SCO costs roughly five thousand dollars¹⁵. Initial seed funds are required for creating a financially stable organization and to pay for any operational costs. Eventually, support staff will need to be hired to plan, market, and run events to attract supporters and raise funds for the SCO’s mission. Large fundraising events, advertisements, and marketing require funds outside of the charitable donations of the organization, which can be difficult to acquire.

Another difficulty SCOs face is the saturation of today’s market. These organizations must constantly work to be noticed among the dizzying amount of marketing in the world to attract new donors and supporters to their cause. There are roughly one and a half million non-profit organizations in the United States today, with

about fifty thousand new ones created every year¹⁵. The average consumer is bombarded by advertisements and grim statistics from these organizations every day, which can be impersonal and easy to ignore. It is a real challenge for SCOs to stand out in the crowd and connect with supporters.

Once an organization has an adequate number of members and supporters, it can be extremely difficult to turn those supporters into actual donors. With the economic downturn the country has experienced over the past few years, SCOs have taken a hit. Fortunately, reports have shown that charitable giving is slowly recovering from the recession and is up four percent in the most recent reports¹⁶. Unfortunately, the recovery has been the second slowest recovery following a recession since 1971¹⁶. Individuals still care about supporting SCOs, but must be more stringent when constructing budgets for charitable giving. And once an individual becomes a donor, the SCO must work to maintain that donor over time.

With all of the challenges and barriers involved in maintaining an SCO, and the impact of the economic recession, many organizations have been forced to shut down operations. So what separates the failed organizations from the successful ones? I believe the use of social media is a major factor in the continued success of SCOs in today's world. According to Oliver Young at Forrester Research, "marketers who embrace social media will outdistance competition, build community following, and boost loyalty"¹⁷.

Using Social Media to Solve Problems

So why does social media marketing work so well in the social change environment? According to Stacey Monk, social media can be “an invaluable source of funds, ideas, advice, and volunteers” for start-up SCOs with limited funding and support¹. Today’s generation values the innovation and personal experience of social media as well as the convenience and financial transparency involved with online donations.

Innovation

We live in a world where the typical consumer spends an average of thirteen hours online every week⁸. In such a tech-savvy culture, the use of social technology in place of traditional alternatives is valued. In a survey about the organization Epic Change, over two hundred respondents were asked: “What motivated you to participate in Epic Change?”¹⁸. The second most highly rated response was that donors appreciated the organization’s “innovative use of social media and technology”¹⁸. It is noticeable and refreshing when organizations step out of their comfort zone and reach out to communities using exciting and modern methods.

Another consideration is that research shows when people are online, they are scanning instead of reading¹⁹. Social media allows for organizations to post short, sweet messages that are straight to the point. These messages are much more likely to be viewed than the traditional newsletter or email, which can be skipped over for being too long or wordy. If a short social media update by an SCO catches a person’s attention with interesting information, they are likely to click on the organization’s profile to view more. It has been shown that non-donors who interact with an organization online are three and a half times more likely to donate than non-donors who have simply supplied

their email address to an organization, say to sign up for a newsletter²⁰. This all goes back to the “scanning” phenomenon; in our online culture, people are too busy and have too many distractions to read lengthy paragraphs. They want interesting information quickly and easily. And once they have that information, they are likely to share it across their social media network, potentially sending an organization’s information across the globe.

The Internet is a fast-paced environment with many distractions, especially in the social media arena, so organizations must take creative approaches to ensure they are noticed. Some organizations have realized the value in applying pop culture phenomena to their marketing to stand out and catch the eye of today’s consumer. For example, in 2011, comedic actor Charlie Sheen had a public breakdown of sorts in which he used such bizarre phrases as “winning”, “tiger blood”, and “warlock” in interviews, which quickly spread to the Internet²¹. In a matter of hours, these phrases “went viral” and were popping up online almost everywhere one could look. The American Red Cross took advantage of this phenomenon and referenced Sheen’s phrase in an official tweet stating: “We may not collect tiger blood, but we know our donors & volunteers have fierce passion for doing good”²². The tweet earned a huge response, with almost ten thousand people “retweeting” it, or sending the message to their Twitter followers, and even caused a slight increase in blood donations²³. Because they were willing to veer away from standard updates and reference pop culture, the American Red Cross caught people’s attention who may not have noticed them before and gained popularity.

Harnessing the power of pop culture to draw people into the world of social activism is the goal of the Harry Potter Alliance²⁴. With seven books and eight movies, the Harry Potter franchise is wildly successful and loved among children and adults alike.

The Harry Potter Alliance (HPA) was formed as a way to tap into this pop culture phenomenon and use it to encourage Harry Potter fans to “act like the heroes they love by acting for a better world”²⁴. Since their formation in 2009, the HPA has registered hundreds of new voters, donated thousands of books to schools and libraries in the United States and Africa, and produced wide-reaching videos and podcasts to strengthen their social media presence²⁵. In 2010, the Harry Potter Alliance demonstrated how strong their unique following was by winning the Chase Community Giving Contest on Facebook by receiving the most online votes out of almost ten thousand other organizations and received a two hundred and fifty thousand dollar grant²⁶. The HPA has introduced hundreds of thousands of young adults to the world of civic engagement and perfectly demonstrates how thinking outside the box and appealing to people’s specific interests by utilizing innovative technology and mainstream culture can attract and engage new audiences to social change organizations and build a strong community following.

Personal Connection

The Internet and social media have not only changed the way people interact with each other, but also with the way they want to interact with businesses. Our online generation dislikes the formal and impersonal marketing approach of the past. Instead, we want to experience personal interactions with organizations we care about. With more sources of information and opinions immediately available to consumers than ever before, marketers must realize that they should give up “control” of the relationship and instead collaborate with consumers. If not, consumers can quickly and easily tap into their online network and find a competitor to give them what they need. This is true even

in the world of philanthropic organizations. According to Stacey Monk, organizations have to “innovate in order to encourage people to re-engage,” which can be accomplished by honest interaction with donors²⁷. Epic Change uses their social media accounts to work closely with their supporters in order to get feedback on their events, ask for opinions on new ideas, and take suggestions. And they really listen. Each year’s version of “TweetsGiving” has been updated and tweaked based on donor suggestions and continues to be successful and gain new supporters.

Traditional advertising methods are based around the “push” ideology. Marketers push information about their product in front of consumers over and over again until the consumer eventually purchases the product²⁸. This type of marketing is not as effective online where consumers have many distractions and tend to avoid paying attention to things that do not interest them. If an organization is using social media only to send messages about grim statistics or to constantly ask for money, they will probably not develop a strong community of supporters. Instead, organizations need to focus on a “pull” method in which they put engaging information out to the right groups of people and begin to pull customers in to the organization based on their personal interests²⁸. Organizations must find a community of people on social media and engage them in conversation; find out their passions and needs. Only when they have developed an authentic relationship with the audience can an organization be successful.

According to the book *The Dragonfly Effect: Quick, Effective, and Powerful Ways to Use Social Media to Drive Social Change*, to engage others and create a connection, organizations must tap into the audience’s emotions²⁹. One of the best ways to accomplish this is to stress similarities between the audience and the target cause by

telling authentic stories. The organization Kiva is particularly good at making this connection. Kiva is a non-profit organization that works to connect people through microfinance loans to alleviate poverty³⁰. Kiva supporters provide micro-loans, as small as twenty-five dollars, to entrepreneurs across the globe who need capital to create better lives for themselves. The organization's goal is to "replace daunting statistics on global poverty with compelling individual stories" that enables a personal connection with the audience²⁹.

When a potential lender arrives at Kiva's website, they are greeted with personal stories of each one of the entrepreneurs in need of financing. Kiva's product philosophy states: "the first thing you notice are faces; money and organizations are secondary, people are primary"³¹. This is evident in the way the stories are presented focusing on progress instead of poverty. The entrepreneurs are divided based on "type" such as agriculture, entertainment, and health, which enables potential lenders to search for stories of interest and allows for a more personal experience. Once a loan is made, lenders receive updates from Kiva throughout the life of the loan, developing communication and awareness between the two individuals. This strong sense of community is at the heart of Kiva, and brings lenders back again and again to create not only a partnership with someone across the globe, but also an emotional connection.

The use of social media such as Facebook and Twitter, along with the social community on their own site, has always been important to Kiva's development. Kiva's CEO, Matt Flannery uses his own social media accounts "in a very personal way to build two-way empathy"³². Flannery believes that by participating in dialogues on social media he can better understand his company's supporters and make Kiva into a more personal

and appealing organization. This strategy has paid off, as evidenced by a “social invite challenge” Kiva ran in 2011. The organization encouraged users to spread the word and invite others on their social networks to try Kiva for the first time, and in less than twenty-four hours, the site had gained eight thousand new lenders who were able to make a difference in lives of borrowers all over the world³².

This type of global philanthropy would not have been possible if not for the rare opportunities social media provides to organizations. The ability to personally and authentically connect with users, along with the unique community setting of social media sites, encourages the development of wide-reaching and loyal supporters. Social media creates communities of like-minded individuals who self-select based on common interests and who trust each other’s opinions. If one person in the community is passionate about a cause or organization, such as Kiva, it is likely that other members of their community will be attracted to it as well. And if an organization has made an effort to empathize and personally connect with their supporters, those users are likely to pass on positive information about the organization to their networks; essentially creating free, global marketing for the company and a wealth of new supporters.

Convenience

Today’s generation is all about convenience; it seems that everything we need is only a click of a button away. In today’s world, when a person is interested in a social change organization they might “like” the cause’s Facebook page or “follow” the organization on Twitter. As the organization posts social media updates, the person can easily learn more about the cause, interact with the organization, and hopefully become a supporter. The low amount of commitment involved in initially learning about and

supporting an organization with social media is ideal to today's generation. Social media allows a person to casually learn about SCOs and make the transition from outside observer to supporter at their own pace with a low amount of pressure. If, instead, a person new to an organization is initially asked to go door-to-door to recruit others to the cause, they may shy away from becoming involved at all, even if they agree with the organization's mission. It is believed that initial involvement with an organization must be convenient and low-commitment to attract the most supporters²⁹.

When a person decides they do want to share an organization's information with others, a single click on a social media site is all they need. On Twitter, a person can "retweet" an organization's post and share it with their network. According to Jeremiah Owyang, a retweet shows your social network that you found the organization's information so valuable that it needed to be passed on³³. He goes on to say that retweets are vital to content spreading between communities, which leads to causes going viral³³. New supporters of an SCO are much more likely to take the lower-commitment route of spreading information among their social networks than going door-to-door, and they can potentially reach thousands of others with this simple action. Many of the best examples of social good fueled by social media, including TweetsGiving, were spread by the power of the retweet.

This low-commitment approach to activism has led the current generation to be dubbed the "slacktivists". "Slacktivism" is considered the act of engaging in low-commitment online and social media activities, such as "liking" pages and "retweeting" information, which make a person feel as if they are doing good but which actually make little difference³⁴. Malcolm Gladwell stated in a highly debated article that "slacktivism"

creates weak ties that rarely lead to social change, unlike more high-risk activities such as marches and sit-ins³⁵. However others, such as Ben Rattray, founder and CEO of the SCO Change.org, embrace the so-called slacktivists and see them as an important resource. “Having ten million people is more important than ten million dollars”, says Rattray, because he believes that advocacy is less about donations and more about spreading awareness and mobilizing large groups of people³⁶. And slacktivists have shown time and time again, as with TweetsGiving and Blame Drew’s Cancer, that they are excellent at quickly and efficiently spreading information all across the world.

In fact, new research shows that slacktivists are actually more active with philanthropic organizations than their non-social media counterparts. A study by the Georgetown University Center for Impact Communication and Ogilvy Public Relations shows that Americans who participate with philanthropic organizations via social media are twice as likely than non-social media users to volunteer their time or take part in an event for an organization³⁷. These so-called slacktivists are also five times as likely as non-social media users to recruit others to the cause and are actually just as likely to donate money in support of a cause³⁷. Shawn Ahmed, founder of the Uncultured Project, an online movement to connect people and make the world a better place, has likened simple actions, such as supporting an organization on social media, to a “gateway drug” for deeper philanthropic involvement³⁸.

Now, many organizations have begun to realize that acquiring large groups of “slacktivists” is not a wasted effort. Instead, they should view this group of people as their own personal “social champions” and work to attract more of them to their cause³⁹. The most effective way to draw this type of supporter into an organization is with a low-

commitment and high-reward activity, such as a game or a contest. Social media members are hesitant to pass on information, such as requests for donations, to their social network that feels intrusive⁴⁰. An online contest, however, is fun, energizing, and more interesting than simply reading about an SCO, so it will attract more users and these participants are more likely to share the event among their networks. And once a person casually engages with an SCO, it is easier for the organization to then engage them further, such as asking for participation in an event or a donation³⁸. Social media allows organizations to easily offer this type of high-reward activity to supporters, with documented success.

For example, in April 2010, the organization TwitChange was formed to provide relief and assistance to victims of the devastating earthquakes in Haiti. TwitChange aimed to tap into the popularity of celebrity Twitter accounts by creating the first ever celebrity Twitter auction. Participants had the opportunity to bid on a chance to be followed, mentioned, or retweeted by their favorite celebrity, a huge honor in the online world⁴¹. With support from celebrities in every genre, such as Eva Longoria, Kim Kardashian, Demi Moore, Ryan Seacrest, and Demi Lovato, the site received over thirty million hits and over five hundred thousand dollars in bids in the first two weeks⁴¹. TwitChange went on to receive the 2010 Mashable Award for “Most Creative Social Good Campaign” and continues to launch successful campaigns for various charitable organizations. With more celebrities, such as NFL star Troy Palamalu and singer LeAnn Rimes, becoming involved with new each campaign, users continue to be attracted to the excitement and ease of bidding and donating to TwitChange.

Transparency

According to *The Dragonfly Effect*, one of the most important ways to empower people to take action is by showing them that their contribution is actually making a difference²⁹. When people feel that they have uniquely contributed to a cause, they will feel better about their efforts and will be more likely to spread the word or contribute more themselves²⁹. Social media allows for a level of transparency in social change organizations that was not always available in the past, but which fosters loyalty among supporters.

The use of social media drastically minimizes many of the overhead expenses associated with starting and maintaining a social change organization. Take “TweetsGiving” as an example – the entire campaign was accomplished by volunteers using a social media platform. There was no need to spend capital on the typical costs of a campaign including, mailings, marketing, staff, rent for event space, radio and print promotions, or event entertainment. Not only is this beneficial to start-up SCOs, but it means that “free agents”, individual people who are not associated with an established organization but who want to make a difference in the world, now have the opportunity to enact social change, even without starting capital. And supporters can be assured that their donations are actually being used to support the cause in need.

Social media campaigns allow for almost all of the funds raised by a social change organization to go directly to their charitable cause. In 2010, Epic Change launched the site “To Mama With Love”, a collaborative online art project that honors moms across the globe for Mother’s Day and raises funds to invest in women who are changing the world⁴². In less than a week, the site raised nearly seventeen thousand dollars for Mama Kamptoni’s school in Arusha, and it continues to raise money for

various women today⁴². Over ninety-five percent of funds raised through “To Mama With Love” are given directly to the causes it supports. The remaining five percent is used to cover online money transfer fees, donation processing, and dispersal⁴². No funds are spent on outside marketing, which means that more money is able to go directly to those in need. And donors recognize this. According to Meaghan Edelstein, founder of Spirit Jump, donors “want to know their money is actually making a difference and not going to throw parties”²³. This knowledge is especially important in the wake of recent news accusations that thousands of charities and non-profit organizations are falsely reporting their use of charitable donations⁴³.

The social change organization charity:water takes financial transparency to the next level. The organization has guaranteed that one hundred percent of all donations will be used to support their water projects; even credit card fees and salaries are paid for by the organization through corporate sponsorships and separate donations⁴⁴. The organization’s mission is to provide the millions of people around the world without clean water access to water projects in their communities. When a supporter sponsors a water project, they will receive exact GPS coordinates and photos of the community their sponsorship helped when the project is complete. This type of transparency not only shows donors exactly what their money is being used for, but also gives them the emotional satisfaction of seeing the faces of the lives they changed.

Supporters want to see the results of their donations first hand. This is why supporters of the organization Kiva often describe the lending experience as “addicting”. Lenders are able to communicate with their microloan partner and actually witness how the partner uses the loan to improve their life; creating an emotional connection that truly

emphasizes the impact of the supporter's involvement. This is a unique experience for most donors, who may be used to writing a donation check and never hearing from an organization again. Evidence shows that when people are happy and feel satisfied in their efforts, they are more likely to engage again and again to improve the lives of others²⁹.

Social Media and Public Health

The evolution of today's society into a culture focused around technology has also had an impact on public health. In accordance with the "groundswell" phenomenon, health care information is increasingly being accessed on the Internet. Just as consumers rely on their social networks for information and opinions on social change organizations, they also trust each other more and more for information about their health.

In the wake of the recent economic recession, access to affordable healthcare has plummeted. The cost of employer-sponsored insurance premiums has risen by one hundred and thirteen percent in the past few years and enrollment in Medicaid, which provides coverage to low-income families, has increased⁴⁵. With over half of the nation's health spending focused on hospital care and physician visits, many people have turned to the Internet and social media communities for information and self-diagnosis as a way to cut costs⁴⁵. The latest *Harris Interactive Poll* in August 2011 surveyed one thousand and nineteen U.S. adults about their habits of using the Internet to find health information. The poll found that seventy-four percent of adults have gone online to look for health information and sixty percent of those adults reported doing so in the last month⁴⁶. The number of people polled who say they use the Internet to find health information "often"

and who report their searches as “successful” has increased annually and ninety percent of adults polled believe the health information they find is reliable⁴⁶.

With so much information available to consumers for free on the Internet, it is easy to understand why many adults are choosing to skip expensive physician appointments and insurance fees in favor of online health information. Medical websites, such as the popular community known as WebMD, have become a staple in the typical American’s health care regimen. The *Harris Interactive Poll* reports that sixty-two percent of adults use medical websites for the majority of their search for health information, with community forums and social media sites following behind⁴⁶. A popular feature of WebMD is the “Symptom Checker,” a tool that allows users to indicate the symptoms they are experiencing and then provides potential diagnoses, outcomes and treatment options; much like a virtual physician appointment⁴⁷. However, unlike traditional physician appointments, online resources are free, provide almost instant results, and require no time off work or away from the family. These factors are especially satisfying in our budget-conscious society that craves instant gratification. However, some studies show that misdiagnosis of certain symptoms is becoming common, leading to improper treatment and potential worsening of the illness⁴⁸. This data emphasizes the need for “e-patients” to verify the accuracy of the information they seek online and to discuss their symptoms further with their physician.

As the Internet is becoming a widely valued source of health information, health care providers, medical societies, and public health officials are realizing the need to provide online information that is relevant to their users. Many physicians and health care systems are now providing personal health records (PHRs) that allow patients to view

their medical files and test results from home on the Internet. Research shows that about seven percent of Americans have used PHRs, but the number is increasing each year⁴⁹.

My own physician recently introduced access to an online PHR and I can say, as a member of the “online generation,” that I value the innovation of the service and the feeling of partnership it inspires with my physician. Whereas patients used to be completely dependent on medical personnel for any information and interpretation of their medical records, we can now have access to and ownership of our health information at all times. I believe this change in the patient-physician relationship encourages patients to spend more time researching their own health issues and empowers them to have a more active role in their health care. In fact, the *Harris Poll* reports that fifty-seven percent of adults who search for health information online go on to discuss that information with their physicians, and the same percent of adults conduct further research after meeting with their physician; a number that has steadily increased throughout the years⁴⁶.

Not only has the Internet changed the way we look at personal health care, but it has also become a major source of information for public health officials. Traditional methods of epidemiology focus on a process known as syndromic surveillance, a time-consuming and labor-intensive project that relies on collecting data from hospitals, clinics, and other health services across the nation⁵⁰. The Centers for Disease Control and Prevention uses this information to compile weekly outbreak reports, which typically are released two weeks after actual events⁵⁰. This lag makes it difficult for public health officials to predict outbreaks and be prepared for medical needs as they arise. More and

more public health organizations are now turning to the Internet to track the spread of disease and illness.

Public health organizations have found ways to tap into the power of the Internet to collect epidemiological data. Using query programs, public health organizations can monitor the number of times a specific keyword or phrase is entered into popular search engines, such as Google and Yahoo. This data essentially informs researchers of how many people are searching for information related to a certain illness or disease, which would hopefully correspond to the prevalence of the disease at that time. For example, researchers used Google queries to track the spread of *methicillin-resistant Staphylococcus aureus*, or MRSA, by recording the frequency of Google searches for the phrases “MRSA”, “staph”, and “mersa”⁵¹. The report indicated that a steady rise in occurrences of those keywords appearing in search engines matched the increase in hospitalizations for MRSA during the same time period⁵¹. Many similar studies have been conducted, including Google’s own query program known as Google Flu Trends. The data collected by the program is closely matched to official influenza surveillance data from countries across the globe⁵². Google Flu Trends is updated every day and hopes to assist with early detection of disease outbreaks.

The use of social media, especially Twitter, to gather public health data is a newer concept and one that shows even more reliability than query searches. Studies have shown that Twitter users extensively share health information and seek health advice through their tweets⁵³. Because of the nature of Twitter, health data can be collected in real-time and with more context than is available with query searches. When researchers use search engine queries, they know how many times their keyword was searched, but

they don't know the reason behind why it was searched. Data collected from Twitter is more contextual because the entire tweet is available, allowing researchers to weed out tweets that may include the needed keyword but do not correspond to the study. For example, a recent news story about influenza may increase the number of Google searches for the term "influenza," skewing research results by indicating a higher, and inaccurate, number of influenza cases. Although the same news report may increase the number of tweets including the phrase "influenza", researchers would be able to ignore those instances that only reference the news story instead of reporting actual symptoms, resulting in more accurate data.

The potential impact of collecting public health data from Twitter has prompted organizations such as the Centers for Disease Control and Prevention and the National Institutes of Health to fund projects that improve social media research tools. The U.S. Office of the Assistant Secretary for Preparedness and Response (ASPR) recently launched a contest urging developers to create an app that public health officials can use to understand the development of disease trends from Twitter data⁵⁴. The winning app should be able to deliver the top five trending diseases in different geographical locations to local public health officials to provide those officials with disease information in their area and an advance signal of any potential public health emergencies⁵⁴. Because social media research provides real-time data, it allows officials to more quickly respond to potential outbreaks and better anticipate the need for medications and health services. Social media is also helpful for informing officials of the public sentiment concerning an outbreak, as was demonstrated in studies of the 2009 Influenza A H1N1 epidemic⁵⁵.

Overall Impact

In the face of the ever-changing needs of our society, social media seems to be the approach that provides the innovation and convenience needed to connect with today's generation. All types of organizations, from social change to public health, can benefit from the unique opportunities social media provides for connecting with the audience, engaging supporters, and spreading information. As a member of the tech-savvy generation and a passionate supporter of advocacy for public health initiatives, I believe that the proper use of social media can truly make an impact on today's world.

For example, I believe that the marriage of social media advocacy and public health research could be just what this country needs to battle the epidemic of chronic diseases such as heart disease and cancer, which account for the nation's top two causes of death⁵⁶. By implementing the tactics mentioned previously, public health organizations could use social media to gather information and track the prevalence of chronic disease and the behavioral risk factors for disease, such as poor nutritional habits and smoking. These organizations could then use social media communities to foster intimate relationships with those groups of people demonstrating the highest level of behavioral risk factors and empower these communities to have a more active role in their health. Social media would allow health information to be presented in ways proven to engage today's generation, using short, personal messages and allowing opportunities for reward, such as online weight loss challenges or smoking cessation contests, for example. By approaching the chronic disease epidemic in a way that the younger generation is known to respond to, public health organizations would have the chance to truly impact and improve the quality of life of this population and slow the impact of chronic disease.

I truly believe that the wide-reaching capabilities of social media give us the power to raise awareness and improve lives all around the globe, unlike anything we have seen before. The most successful campaigns in the near future will be lead by organizations that embrace social media and I am sure that my career will continue to be impacted by new developments in the social media arena.

Sources

1. Israel, Shel. "Twiterville Neighborhoods: Stacey Monk, Epic Change." *Global Neighborhoods*. N.p., 25 Mar. 2009. Web. 27 June 2012.
2. "Mission." *EPIC CHANGE*. Epic Change, n.d. Web. 27 June 2012.
3. Fine, Victoria. "Tanzanian Schoolkids Tweet Their Thanks For Global Donations." *The Huffington Post*. TheHuffingtonPost.com, 23 Oct. 2009. Web. 27 June 2012.
4. "Positively Inspired Change Campaigns." *SXSW Schedule 2012*. SXSW, 2012. Web. 27 June 2012.
5. Edelstein, Meaghan. "8 Tips for a Successful Social Media Cause Campaign." *Mashable*. N.p., 10 May 2010. Web. 28 June 2012.
6. Olanoff, Drew. "Donation By Action: The New Social Charity Model." *Mashable*. N.p., 30 Dec. 2009. Web. 28 June 2012.
7. Fox, Zoe. "How (RED) United the Social Web in the Fight Against AIDS." *Mashable*. N.p., 25 May 2012. Web. 28 June 2012.
8. Smith Ellis, Susan. "Why Social Media Is a Game-Changer for Causes." *Mashable*. N.p., 17 Sept. 2010. Web. 28 June 2012.
9. "Social Media." *Merriam-Webster*. Merriam-Webster, n.d. Web. 27 June 2012.
10. Bullas, Jeff. "48 Significant Social Media Facts, Figures and Statistics Plus 7 Infographics." *48 Significant Social Media Facts, Figures and Statistics*. JeffBullas.com, n.d. Web. 27 June 2012.
11. Meis, Scott. "Groundswell Learnings - Part 1." *Social Media Snippets*. N.p., 3 Sept. 2008. Web. 27 June 2012.

12. "WWF - WWF." *WWF*. World Wildlife Foundation, n.d. Web. 09 July 2012.
<<http://wwf.panda.org/>>.
13. "The Salvation Army : Doing the Most Good.â" .*" The Salvation Army: Home*. N.p., n.d. Web. 09 July 2012.
<http://www.salvationarmyusa.org/usn/www_usn_2.nsf>.
14. "One for One Movement." *TOMS.com*. TOMS Shoes, n.d. Web. 9 July 2012.
<<http://www.toms.com/our-movement>>.
15. Ivie, Kristin. "Want to Start a Nonprofit? Think Again." *Social Citizens*. The Case Foundation, 29 Sept. 2009. Web. 09 July 2012.
<<http://www.socialcitizens.org/blog/start-nonprofit>>.
16. "Has America's Charitable Giving Climbed Out of Its Great Recession-fueled Trough?"*The Center on Philanthropy*. IUPUI, 19 June 2012. Web. 09 July 2012.
<<http://www.philanthropy.iupui.edu/news/2012/06/pr-GivingUSA2012.aspx>>.
17. Odden, Lee. "Making a Case for Social Media." *Top Rank*. N.p., 2009. Web. 28 June 2012.
18. Monk, Stacey. "What You Said." *The Epic Change Blog*. Epic Change, 26 Apr. 2012. Web. 12 July 2012. <<http://epicchangeblog.org/2012/04/26/what-you-said/>>.
19. Adler, Daniel. "Twenty-One Top Twitter Tips." *Forbes*. Forbes Magazine, 31 July 2009. Web. 09 July 2012. <<http://www.forbes.com/2009/07/31/top-twitter-tips-entrepreneurs-technology-twitter.html>>.
20. Livingston, Geoff. "HOW TO: Turn Slacktivists into Activists with Social Media." *Mashable*. N.p., 13 May 2010. Web. 09 July 2012.
<<http://mashable.com/2010/05/13/slacktivists-activists-social-media/>>.

21. Beam, Christopher. "Where Charlie Sheen's Crazy Words Come From." *Slate Magazine*. N.p., 4 Mar. 2011. Web. 06 Aug. 2012.
<<http://www.slate.com/articles/arts/culturebox/2011/03/sheenglish.html>>.
22. "American Red Cross Tweet." *Twitter*. American Red Cross, 2 Mar. 2011. Web. 12 July 2012. <<https://twitter.com/redcross/status/42947546695467008>>.
24. Beam, Christopher. "Sheenglish." *Slate Magazine*. N.p., 4 Mar. 2011. Web. 12 July 2012. <<http://www.slate.com/articles/arts/culturebox/2011/03/sheenglish.html>>.
23. Sniderman, Zachery. "How Non-Profits Are Tapping Internet Memes and Pop Culture." *Mashable*. Mashable Social Media, 30 Aug. 2011. Web. 12 July 2012.
<<http://mashable.com/2011/08/30/pop-culture-non-profits-memes/>>.
24. "What We Do." *The Harry Potter Alliance*. N.p., n.d. Web. 13 July 2012.
<<http://thehpalliance.org/what-we-do/>>.
25. "Success Stories." *The Harry Potter Alliance*. N.p., n.d. Web. 13 July 2012.
<<http://thehpalliance.org/what-we-do/success-stories/>>.
26. "HPA for the Win." *The Harry Potter Alliance*. N.p., n.d. Web. 13 July 2012.
<<http://thehpalliance.org/action/campaigns/hpafw/>>.
27. Fine, Allison. "How a Grass-Roots Charity Listens to Its Supporters." *The Chronicle of Philanthropy*. N.p., 13 Dec. 2011. Web. 15 July 2012.
<<http://philanthropy.com/article/Listening-to-Donors-on/130086/>>.
28. Abernethy, Jennifer. *The Complete Idiot's Guide To Social Media Marketing*. New York: Alpha, 2010. Print.

29. Aaker, Jennifer Lynn., Andy Smith, and Carlye Adler. *The Dragonfly Effect: Quick, Effective, and Powerful Ways to Use Social Media to Drive Social Change*. San Francisco: Jossey-Bass, 2010. Print.
30. "About Us." *Kiva*. N.p., n.d. Web. 17 July 2012. <<http://www.kiva.org/about>>.
31. Flannery, Matt. "Kiva and the Birth of Person-to-Person Microfinance." *Kiva*. MIT Press, 2007. Web. 17 July 2012.
<http://media.kiva.org/INNOV0201_flannery_kiva.pdf>.
32. Silverman, Matt. "How Kiva.org's CEO Uses Social Media to Spark a Dialogue of Change." *Mashable*. N.p., 20 Sept. 2011. Web. 17 July 2012.
<<http://mashable.com/2011/09/20/kiva-matt-flannery-social-media/>>.
33. Kanter, Beth. "First There Was Trick or Tweet, and Now Tweetsgiving!" *Beth's Blog: Nonprofits and Social Media*. Typepad.com, 25 Nov. 2008. Web. 18 July 2012.
<http://beth.typepad.com/beths_blog/2008/11/first-there-was-trick-or-tweet-and-now-tweetsgiving-.html>.
34. "Social Media - Revolutionary Movement or Enabler of "Slacktivism"?" *Center for Social Innovation*. Stanford Graduate School of Business, 13 Oct. 2010. Web. 18 July 2012. <<http://csi.gsb.stanford.edu/slacktivism>>.
35. Gladwell, Malcolm. "Small Change." *The New Yorker*. The New Yorker, 4 Oct. 2010. Web. 18 July 2012.
<http://www.newyorker.com/reporting/2010/10/04/101004fa_fact_gladwell>.
36. Sniderman, Zachery. "How Social Good Has Revolutionized Philanthropy." *Mashable*. Mashable Social Media, 17 Sept. 2010. Web. 10 July 2012. <<http://mashable.com/2010/09/17/social-good-philanthropy/>>.

37. . "Slacktivists Doing More Than Clicking in Support of Causes." *Georgetown University*. Ogilvy PR, 28 Nov. 2011. Web. 18 July 2012.
<http://csic.georgetown.edu/OPR_SM_GT_Slacktivists_FINAL.pdf>.
38. Kessler, Sarah. "Why Social Media Is Reinventing Activism." *Mashable*. N.p., 9 Oct. 2010. Web. 19 July 2012. <<http://mashable.com/2010/10/09/social-media-activism/>>.
39. "Unraveling the Myth of Slacktivism." *Inspiring Generosity*. N.p., 25 Oct. 2011. Web. 19 July 2012. <<http://social.razoo.com/2011/10/unraveling-the-myth-of-slacktivism/>>.
40. "Why Does Slacktivism Exist? What Can Marketers Do to Overcome This Issue?" *GENERATION 'Y BOTHER': SOCIAL MEDIA AND SLACKTIVISM*. N.p., 4 Apr. 2012. Web. 19 July 2012. <<http://gen-y-bother.blogspot.com/>>.
41. "Emergency Aid in Haiti | TwitChange." *TwitChange*. N.p., n.d. Web. 19 July 2012. <<http://twitchange.com/evahelpinghaiti/>>.
42. "Show a Mama You Love Her This Mother's Day. Change the World. #ToMamaWithLove:." *ToMamaWithLove*. Epic Change, n.d. Web. 09 July 2012. <<http://www.tomamawithlove.org/more-info>>.
43. Ducey, Joe. "Where Should You Give? Thousands of Nonprofits Misreporting Fundraising Costs." *KNXV*. ABC, 31 May 2012. Web. 06 Aug. 2012. <http://www.abc15.com/dpp/news/local_news/investigations/where-should-you-give-thousands-of-nonprofits-misreporting-fundraising-costs>.
44. "Charity: Water." *Donate*. N.p., n.d. Web. 19 July 2012. <<http://www.charitywater.org/donate/>>.

45. "U.S. Health Care Costs: Issue Modules, Background Brief - KaiserEDU.org, Health Policy Education from the Henry J. Kaiser Family Foundation." *U.S. Health Care Costs: Issue Modules, Background Brief - KaiserEDU.org, Health Policy Education from the Henry J. Kaiser Family Foundation*. Kaiser, n.d. Web. 06 Aug. 2012. <<http://www.kaiseredu.org/issue-modules/us-health-care-costs/background-brief.aspx>>.
46. Harris Interactive. "The Growing Influence and Use of Health Care Information Obtained Online." *Harris Interactive*. Harris Interactive, 15 Sept. 2011. Web. 6 Aug. 2012. <<http://www.harrisinteractive.com/NewsRoom/HarrisPolls/tabid/447/ctl/ReadCustom%20Default/mid/1508/ArticleId/863/Default.aspx>>.
47. "WebMD Symptom Checker." *Symptom Checker from WebMD. Check Your Medical Symptoms*. WebMD, n.d. Web. 06 Aug. 2012. <<http://symptoms.webmd.com/>>.
48. "Danger of Dr Google: 25 per Cent of Women Misdiagnose Themselves on the Internet." *Mail Online*. Daily Mail, 17 Apr. 2012. Web. 06 Aug. 2012. <<http://www.dailymail.co.uk/health/article-2131275/Danger-Dr-Google-25-cent-women-misdiagnose-internet.html>>.
49. Steciw, Anne. "National Survey Finds PHR Usage Is Still Low, but Growing." - *Health IT Pulse*. Health IT Exchange, 15 Apr. 2010. Web. 06 Aug. 2012. <<http://searchhealthit.techtarget.com/healthitexchange/healthitpulse/national-survey-finds-phr-usage-is-still-low-but-growing/>>.

50. Page, Doug. "Public Health Officials Track Disease Outbreaks with TwitterTwitter Monitoring Done in Real Time, Can Detect Outbreaks Sooner than Traditional Means of Polling Hospitals." *HomeLand1*. N.p., n.d. Web. 06 Aug. 2012.
<<http://www.homeland1.com/homeland-security-columnists/doug-page/articles/1267189-public-health-officials-track-disease-outbreaks-with-twitter/>>.
51. Stafford, John. "Following Google Flu Trends, Researchers Use Queries to Track MRSA." *Scope Blog*. N.p., 16 June 2011. Web. 06 Aug. 2012.
<<http://scopeblog.stanford.edu/2011/06/16/following-google-flu-trends-researchers-use-queries-to-track-mrsa/>>.
52. "Flu Trends." *Google*. N.p., n.d. Web. 06 Aug. 2012.
<<http://www.google.org/flutrends/about/how.html>>.
53. "Using Twitter for Public Health Surveillance of Dental Pain." *ScienceDaily*. ScienceDaily, 18 July 2011. Web. 06 Aug. 2012.
<<http://www.sciencedaily.com/releases/2011/07/110718151602.htm>>.
54. Mashable. "Twitter Can Track Disease - Can It Predict Outbreaks?" *Sickweather.com*. Sickweather, 8 June 2012. Web. 6 Aug. 2012.
<<http://www.sickweather.com/press/>>.
55. Signorini, Alessio, Alberto Maria Segre, and Philip M. Polgreen. "The Use of Twitter to Track Levels of Disease Activity and Public Concern in the U.S. during the Influenza A H1N1 Pandemic." *National Center for Biotechnology Information*. U.S. National Library of Medicine, 04 May 2011. Web. 06 Aug. 2012.
<<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3087759/>>.

56. CDC. "Leading Causes of Death." *CDC.gov*. Centers for Disease Control and Prevention, 27 Jan. 2012. Web. 06 Aug. 2012.
<<http://www.cdc.gov/nchs/fastats/lcod.htm>>.